



## SINGULAR THERAPEUTIC PROJECT AND MULTIPROFESSIONAL TEAM IN CLINICAL COMPLEX CASE MANAGEMENT: AN EXPERIENCE REPORT

PROJETO TERAPÊUTICO SINGULAR E EQUIPE MULTIPROFISSIONAL NO MANEJO DE CASO CLÍNICO COMPLEXO: RELATO DE EXPERIÊNCIA

PROYECTO TERAPÉUTICO ÚNICO Y EQUIPO MULTIDISCIPLINAR EN EL MANEJO DE CASO CLÍNICO COMPLEJO: ESTUDIOS DE CASO

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### ABSTRACT

**Objective:** reporting the experience of a multidisciplinary health team in developing a care plan for a patient with Werdnig Hoffmann Syndrome, based on the theoretical framework of Singular Therapeutic Project. **Method:** a descriptive study type reporting reflective nature experience, held in a hospital of Sao Paulo from August/2012 to January/2013. The participants were: the patient, his mother, and the multidisciplinary team. There were performed workshops with guided discussions in the framework of the Therapeutic Project for Single Individuals, health needs being raised the patient and the caregiver to developing the intervention plan based on individual vulnerabilities, social and political and programmatic case. **Results:** there was the construction of a new way of working as a team. **Conclusion:** Singular Therapeutic Project as a humanistic tool proved to be powerful and helpful to illustrating the implementation of a care management device which can equip complex health actions. **Descriptors:** Spinal Muscular Atrophies of Childhood; Patient Care Team; Child Care; Nursing.

### RESUMO

**Objetivo:** relatar a experiência de uma equipe multiprofissional em saúde na elaboração de um plano de cuidados para um paciente portador da Síndrome de Werdnig Hoffmann, alicerçado no referencial teórico do Projeto Terapêutico Singular. **Método:** estudo descritivo, tipo relato de experiência de cunho reflexivo, realizado em um hospital paulista no período de agosto/2012 a janeiro/2013. Participaram da pesquisa: o paciente, sua mãe, e a equipe multiprofissional. Realizaram-se oficinas de trabalho com discussões pautadas no referencial do Projeto Terapêutico Singular para Indivíduos, sendo levantadas necessidades de saúde do paciente e da cuidadora, para elaborar o plano de intervenção baseando-se nas vulnerabilidades individuais, sociais e político-programáticas do caso. **Resultados:** verificou-se a construção de uma nova forma de trabalhar em equipe. **Conclusão:** o Projeto Terapêutico Singular como ferramenta humanística, mostrou-se potente e foi útil para exemplificar a implementação de um dispositivo de gestão do cuidado o qual pode instrumentalizar ações complexas de saúde. **Descritores:** Atrofias Musculares Espinais da Infância; Equipe de Assistência ao Paciente; Cuidado da Criança; Enfermagem.

### RESUMEN

**Objetivo:** presentar la experiencia de un equipo multidisciplinario de salud en el desarrollo de un plan de atención para un paciente con Síndrome de Werdnig Hoffmann, con base en el marco teórico del Proyecto Singular Terapéutico. **Método:** un tipo de estudio descriptivo de informe de experiencia, de naturaleza reflexiva, que tuvo lugar en un hospital de Sao Paulo a partir de agosto/ 2012 a enero/2013. Los participantes fueron: el paciente, su madre, y el equipo multidisciplinario. Hubo talleres con discusiones guiadas en el marco del Proyecto Terapéutico para personas individuales, las necesidades de salud están planteando el paciente y el cuidador, para desarrollar el plan de intervención basado en vulnerabilidades individuales, caso social y política y programática. **Resultados:** hubo la construcción de una nueva forma de trabajar en equipo. **Conclusión:** el Proyecto Terapéutico Singular como herramienta humanista demostró ser potente y útil para ilustrar la aplicación de un dispositivo de gestión de la atención que se puede equipar las acciones de salud complejas. **Descritores:** Atrofias Musculares Espinales de la Infancia; Grupo de Atención al Paciente; Cuidado de Niños; Enfermería.

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## INTRODUCTION

The Werdnig Hoffmann Syndrome is a neurodegenerative disease of genetic etiology; pathology included in the group known as Spinal Muscular Atrophies (AME). It is considered the main fatal autosomal recessive disorder, and its occurrence approximately one for every ten thousand births.<sup>1,2</sup> This syndrome is characterized mainly by the secondary muscle atrophy, degeneration of motor neurons in the anterior horn of the spinal cord.<sup>3</sup>

Clinically, AME comprise four pathologies classified according to the age of onset and degree of motor impairment. Type 1, called AME Child or Werdnig Hoffmann Syndrome, object of this study, is presented as more severe form of the disease. It manifests earlier between the prenatal period and six months or immediately after birth and features, due to severe motor and respiratory impairment.<sup>4</sup> In type 1, the children do not roll or sit without support, and usually do not survive after three years old.<sup>1,4</sup>

Clinical manifestations are characterized by hypotonia, areflexia, muscle atrophy of the extremities and trunk, fine tremor of the fingers and tongue fasciculations often leading to difficulty in swallowing and suction. Affected children have a significant loss of muscle mobility, including motor skills previously acquired.<sup>3,5</sup> All muscles are affected by neurogenic atrophy process, except the diaphragm, the muscles of the extremities and the eye muscles, however, skin sensitivity the sphincter control and presenting the cognitive within the normal range in most patients.<sup>3,5</sup>

Many of the affected individuals have significant respiratory impairment, which often evolves into mechanical ventilation and tracheostomy. However, the main cause of death in these patients is related to the weak respiratory system, due to the increased susceptibility to respiratory infections and persistent accumulation of secretions in the lungs and oropharynx.<sup>6</sup>

Given the above, it is necessary to care planning in a systematic way and integral to enhancing the responsiveness of health services to the individual needs and families with chronic and syndromic degenerative diseases. The care plan should be designed from a multidisciplinary work as a team in which each health professional develops complementary actions in order to promote the comprehensive health care.

The multidisciplinary approach is a strategy for a reorganization of health care that prizes for the quality of services.<sup>7</sup> This concept requires that practitioners use their unique knowledge, based on different decision-making logical and care, are shared, what points beyond labor relations, knowledge and interpersonal relations. Such articulation implies a connection of different work processes, work together and value the recognition by others of your need for health care.<sup>8-10</sup>

As proposed, has been discussed in the national literature, from the publication of the National Humanization Policy (PNH) in 2003 therapeutic strategies that are made to work in health production practices to promote changes in the model of care/management of clinical cases complexes. Among the HNP devices highlights the Singular Therapeutic Project (PTS), understood as a model of singling health practices.<sup>11</sup> Such a device emerges as grounded case management tool in the set of articulated therapeutic procedures. The PTS results of the discussion of actions of care of a multidisciplinary team, directed to an individual subject or collective.<sup>12</sup>

The PTS is produced in "a variation of clinical case discussion".<sup>13</sup> It is based on meetings in which health professionals exchange perceptions and build a comprehensive understanding of the sick individual, which is subsidized by the design of interventions on the case. In addition, technical meetings are part of the work process in health and allow the exchange of information and experiences of everyday life, providing a participatory and sharing skills' process<sup>14</sup>, which focuses on pedagogical practice, creative activity and triggering processes internal review of values and behaviors and collective construction of knowledge.<sup>11,15</sup> PTS consists of four stages: 1) the diagnosis; 2) goal setting; 3) the division of responsibilities and tasks between team members; and 4) the reevaluation.<sup>13</sup> However, this innovative strategy to care demand health teams new forms of organization for its development. Thus, teamwork must overcome the fragmentation of professions, for producing an essentially focused practice in the unique needs of the subjects.

Because of the degenerative nature of neuromuscular disorders, added to the fact that to date there is no cure for the disease, unless the palliative and preventive treatment, it is considered that the large current struggle is not only to maintain the survival of individuals the syndrome, but also

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offer multidisciplinary interventions in order to provide a better quality of life and minimize suffering and clinical complications. Thus, it acts as a key component for health care, the multidisciplinary team, which has a unique knowledge and whose act must be founded on the principle of comprehensiveness and humanization.<sup>16-17</sup> The professionals of this team play leadership roles and can share their view as to what is the scope of professional practice necessary to realize the promise and potential of health care. However, the scientific literature is still limited and has to be published with regard to the description of Singular Therapeutic Projects managed in the light of a multidisciplinary team of health in the context of AME.<sup>3</sup>

## OBJECTIVE

- Reporting the experience of a multidisciplinary health team in developing a care plan for a patient with Werdnig Hoffmann Syndrome, based on the theoretical framework of Singular Therapeutic Project.

## METHODOLOGY

Manuscript originated from the monograph << **Performance of a multidisciplinary health team in Werdnig Hoffmann Syndrome: a methodological research** >> submitted to the Postgraduate Program *Latu Sensu* in Integrated Multidisciplinary Residence in Maternal-Infant Marília Medical School - FAMEMA, 2013.

This is a descriptive study of type reporting reflective experience. The subjects involved in this study were: the patient with Werdnig Hoffmann syndrome, his mother, and the professional staff of the Residence Multidisciplinary Integrated in Maternal-Infant Health, namely: social worker, physical therapist, speech therapist, nurse and dietitian. To protect the identity of participants opted for the use of acronyms (PC - patient; M - the patient's mother, NDE - multidisciplinary team of Residence).

The study was conducted at the Maternal and Child Hospital Complex Hospital of FAMEMA II, located in a city located. The research was conducted in the period August 2012 to January 2013.

At the time of data collection the participants were invited to participate in the study voluntarily, being asked their nods through the Informed Consent Term. Data collection was performed in the patient's chart in order to obtain relevant information such as medical history and evolution of the

disease during the period of hospitalization, from the clinical view of each professional. Then, the mother of the patient was submitted to a semi-structured interview and supplemental data for more valuable information on aspects related to pregnancy, childbirth, psychomotor development, diagnosis of disease, progression of the disease, the more obvious changes, prospects and her positioning against sickness.

Two-hour weekly workshops were held, lasting a month, totaling four meetings. Such meetings took place under the coordination of guiding the study, observation of the researcher and with the participation of the five members of the multi residence which jointly discussed the case and the clinical management of it, in a perspective where the nexus knowledge/skills/attitudes combined with practice comprehensive care was rescued. Therefore, it was used during the workshops a systematized script Therapeutic Project for Single Individuals (PTSI)<sup>11</sup>, which directed the discussions of the multidisciplinary team based on the procedural moments for the conduct of the project.

For the beginning of the workshop, we use the following starter question: "How come the PC health status? What are the health needs identified in the situation? ", Then being asked to professionals describe such experiences which were brought to the discussion.

The meetings which are supported by PTSI, consisted of discussion of demographic and clinical data of the patient, graphic elaboration of family arrangement (Familiogram), patient history and clinical actions already carried out by various professionals, assessing vulnerabilities, the pact if the goals clinical and preparation of a proposal for intervention. Initially empirical reports were made by observing the researcher and that were recorded in a diary. These reports were included all clinical aspects of the patient, interventions, as well as the synthesis of the issues discussed during the workshops by the multidisciplinary team. The records produced in the workshops were used for construction of the care plan.

This study was submitted to the Institutional Review Board of the Marília Medical School (FAMEMA); and was approved under the protocol number 640/12.

## RESULTS

According to the information extracted from the report of each professional plus medical record information and interview with

M (patient's mother). PC is male and at the time the data were collected was presented with two years and one month old, hospitalized for more than one year and nine months in the hospital. PC was considered critical patient demand for complex care on the part of M, the NDE and the inpatient unit staff, together with the dependence of light health technologies, light-hard and hard to survive. It had a diagnosis of spinal amyotrophy progressive type I, as already mentioned, with motor difficulties in control of upper and lower limbs and neck, with no support of this, plus tables of recurrent respiratory infections since the two months prior to the hospitalization. With regard to family history, the child's mother does not recognize relatives with the same diagnosis or any type of genetic disease.

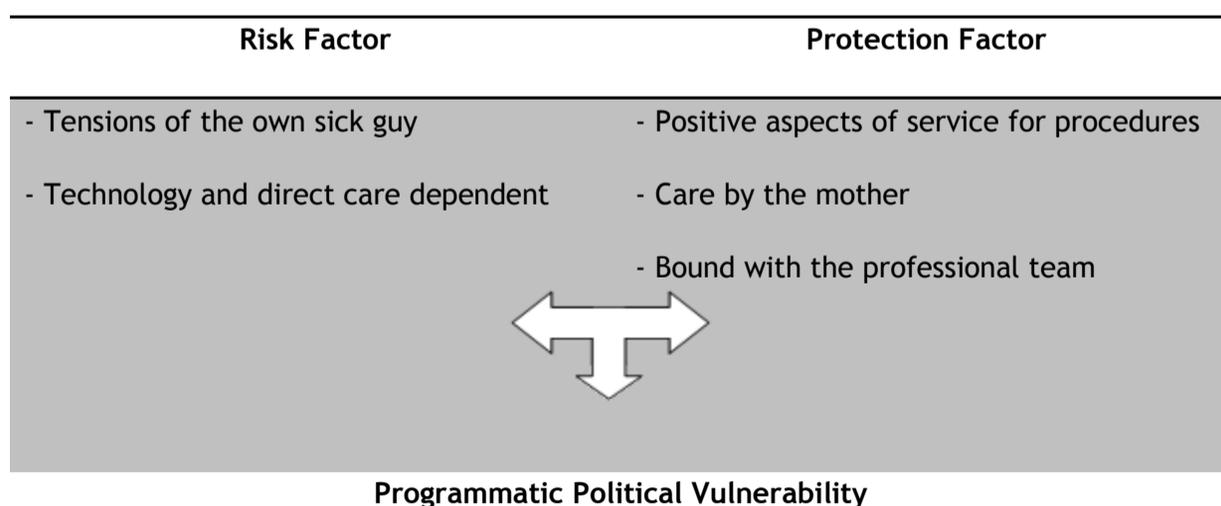
At four months, PC was admitted to the intensive care unit with septic shock secondary to pneumonia. On that occasion, had acute respiratory failure and underwent endotracheal intubation and mechanical ventilation. After the failure of several of weaning attempts and submitted by severe respiratory compromise, underwent tracheostomy. In the same period, due to dysphagia, underwent gastrostomy to diet therapy. The diagnosis was confirmed on eight months for the realization of molecular test indicating the absence of SMN1 gene copy and two copies of the presence of SMN2 gene.

It was found in the unit of pediatric care production, in good general condition, conscious, contactant and susceptible to facial expressions. It presented reasoning and response to stimuli, interacting with the

environment and with people mainly with looking at mechanical pressure controlled ventilation with suction system of oral cavity, hypersecretive, paradoxical breathing, auscultation with wheezing and snoring. Hemodynamically stable, without the use of vasoactive drugs and cardiovascular system preserved. Showed generalized hypotonia, trunk and neck affection, muscle paresis of the upper limbs with minimal movement of the wrist (flexion and extension), presented in semiflexion knees due to the use of cushions, as possessed important muscle shortening, subtle movements of the ankle and toes and feet equinovarus. The gastrointestinal system showed lower intestinal motility, with alternating constipation and diarrhea episodes, receiving enteral diet industrialized associated with soft-fat diets, soups, juices and water. Regarding the immune system, staff reported being depleted, having frequent respiratory and gastrointestinal infections and reside in a hospital environment susceptible to diseases.

**DISCUSSION**

With regard to the identified health needs, the NDE listed the care required by patients as those responsible for the maintenance of life, such as air permeability, nutrition, medication administration, personal hygiene, orofacial and tactile stimulation, positioning members, infection prevention or treatment of these, in addition to health education with M. transcribe in Figure 1 the evaluation scheme vulnerability<sup>11</sup>, which allowed us to analyze the PC problem situation, from the look of the NDE.



**Figure 1.** Balance of vulnerabilities - Marília, SP, 2013.

Protective factors include positive aspects of service to the patient, identified issues arising from the presence of the mother and the completion of procedures necessary for the maintenance of PC and life of the bond.

With regard to risk factors, there is a preponderance of tensions arising from the subject himself against sickness, ie the pathophysiological changes of spinal muscular atrophy. We emphasize the political and

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programmatic vulnerability identified in this context, because of this plan; think in issues related to health services, such as health policies and the organization mode of services<sup>11</sup>. The NDE pointed out that the absence of the Program home care Child, reflected in political and programmatic vulnerability.

Also with regard to this possibility, the NDE reflected on all possible demands that the mother would face on the PC health condition. So the NDE ratified the need for a prepared team to serve you often, besides equipment, adaptations to the home as well as the empowerment of families through health education to deal with the complexity of care.

There were scored as a shadow variable (which distinguishes the case)<sup>15</sup>, groups of individual vulnerability elements, programmatic and social, for example, the difficulty in handling the case of the syndrome in relation to resources and information to family and the quality and efficiency the health system to behold indeed the PC and M. requirements Given this analysis, the NDE reflected on explanatory hypotheses of the case and proposed actions for care.

It realized in M's testimony, the suffering experienced by the same, aware of the closed and PC incurable prognosis, staying all day with PC and away from family, highlighting the fragility of the nuclear family and the consequent detachment of the family. This agonizing suffering was exacerbated by the condition of M, which presented with a diagnosis of depression and difficulties in psychiatric therapeutic follow-up, which favored the lowering of mood swings and affection, appearing most often saddened or even tearful and maintaining minimal contact with the staff. About this problem situation became clear that M longed hospital discharge and home care. With it came a feeling of helplessness on the part of the NDE, but apparently the issue was not consistent with reality, due to the barriers to meet these care peculiarities.

Due to the M diagnosed disorder, the NDE saw an attention beyond the disease, with the provision of psychological support during hospitalization following the psychiatry specialty and drug treatment; also mentioned the possibility of conducting technical courses for income generation and qualification, providing increasing levels of autonomy during hospitalization. In order to foster increased interaction of M with the family opted for the possibility of climbing technicians and nursing assistants for PC, in order to favor their stay

with other family members, for quiet and safe stay, knowing that PC would be taken care of entirely by a nursing professional you trust. It is discussed with reference team of care production unit to sensitize them and jointly implement the actions of the intervention plan, in addition to seeking support network attention about the barriers of a home care.

Some actions punctuated by NDE were able to be performed genetic screening in first-level relatives (parents and siblings) and genetic counseling offering non-directive, for clarification of the genetic condition and genetic risk for family.

NDE said that the case is a challenge for professionals who accompany him, demonstrating feelings of uncomfortable as the poor prognosis and the care process. A member of the NDE, to express his feelings when contacted PC, reported to be experiencing the duality between the care process with the scope of the actions and feelings of inadequacy due to the prognosis, making it too distressing to health professionals and need for care to caregivers. The self-assessment capacity was positive, both in dynamic workshops proposals for the commitment of care protagonists. Saw to PTS potential as a management tool as well as the need to implement it daily in more complex clinical cases of clinical practice.

## FINAL REMARKS

Based on the conducted study, there was the construction of a new way of working as a team, which demonstrated intersections among the subjects with respect and appreciation against the knowing and the doing of the various professions and shared responsibility for the attention paid to the clinical case.

The significance of the discussion of this PTS goes beyond the case itself. The multiplicity of themes that emerged can be managed by different perspectives and approaches, supporting further discussions. The progress of discussions in the workshops held by PTSI has revealed new possibilities, due to the increasingly larger capacity, cyclical analysis of the NDE on the case. PTS sets up a powerful instrument to trigger processes of change in health practices, contributing to the diversification of jobs in health services. Helpful to exemplify the implementation of health practices that take into account the peculiarities of the subjects involved in the care process, however, as well as other arrangements and management devices, the PTS proposed in this work is not the solution to all issues. Do not end here the

possibilities of critical readings of what was presented. This experience report brought up a management device which can equip several complex care actions, grounded in a multidisciplinary team in order to promote activism in the defense and construction of the SUS.

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